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## News and Views

### Freedom of Information and Healthcare Data — The First UK Appeal: Common Services Agency v the Scottish Information Commissioner

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#### Abstract

On the 1st of December 2006, the Court of Session in Edinburgh issued the first decision on Freedom of Information and health data regarding a request for information on incidences of childhood leukemia, in the range of 0 - 14 years, by year and census ward from 1990 to 2003 for the Dumfries and Galloway postal areas. The case, which provides an example for the collision course between the Freedom of Information and Data Protection regime, had been anticipated as a landmark decision, however, due to several problems and inconsistencies it sadly failed to meet those expectations.

#### Keywords

Freedom of Information; Data Protection; personal data; disclosure; Barnardisation

## I. Introduction

On 1 January 2005, the UK received its freedom of information legislation, in the form of the Freedom of Information Act in England and Wales and the Freedom of Information (Scotland) Act in Scotland. Both Acts are broadly similar in most respects. The Acts provide for a general right of access to information held by public authorities, however, subject to a number of exemptions, ranging from personal data to commercial interest. The personal data exemption is of particular interest, as the Acts refer to the Data Protection Act 1998 for a definition. Thus, two diametrically opposite statutes — one promoting a culture of caution and non-disclosure and the other one a culture of openness and disclosure — are linked, or, so it could be argued, on a collision course.<sup>2</sup> This paper will analyse the

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<sup>2)</sup> Laurie, G and Gertz, R., "When Worlds Collide: What are the obligations of the NHS at the interface between data protection and freedom of information regimes?" *Edinburgh Law Review* 2006 10:151-155

first Scottish court decision on a freedom of information/data protection question. While the decision was passed by a Scottish court, the underlying issues have a considerably wider significance relating to the definition of what data the authority holds, personal data and medical research.

On 11 January 2005, the Common Services Agency for the Scottish Health Service (hereinafter 'the CSA') received a request from Mr Michael Collie on behalf of Chris Ballance, a member of the Scottish Parliament, under the Freedom of Information (Scotland) Act 2002 (hereinafter 'FOISA') for information on incidences of childhood leukaemia, in the range of 0-14 years, by year and census ward from 1990 to 2003 for the Dumfries and Galloway postal areas. The CSA refused the request as, in its opinion, (i) the combination of the rare diagnosis, specified age group, small geographical area and low numbers led to individuals being identifiable and therefore falling within the definition of 'personal data' under the Data Protection Act 1998 (hereinafter 'DPA') — 'personal data' being an exempt category of information under FOISA; (ii) having never carried out the analysis of the data by census ward the CSA did not hold the data requested; and (iii) the CSA had a duty of confidence equivalent to that of the clinicians to whom the information were originally disclosed. The applicant did not respond to invitations to discuss accepting alternative data. After requesting that the CSA review its decision and receiving the same response he then turned to the Scottish Information Commissioner (hereinafter 'the SIC') for a ruling.<sup>3</sup>

While accepting that the requested data constituted personal data, the SIC ruled that a perturbed, 'Barnardised' version of the requested table, should be provided in an attempt to maintain anonymity. Barnardisation is a mechanism applied to tables with figures no greater than 4, whereby the numbers are changed by adding 0, +1 or -1. Cells containing 0, however, remain unchanged and cells containing 1 cannot be changed down to a 0. Thus, the SIC held that the CSA was in breach of FOISA for not having provided sufficient advice and assistance as to what information it was able to supply as required under section 15 of the Act. The CSA appealed this decision, which led to the first UK court decision on Freedom of Information and health data in November 2006, when the case was heard before the Court of Session in Edinburgh. The Court refused the appeal and issued its opinion on the 1st of December.

## **II. The Judgment of the Edinburgh Court of Session**

In its opinion, the Court of Session discussed two main issues.

First, the Court discussed the question whether Barnardised data can be considered as 'held' by the CSA and thus are the raw data presented in a particular form, or whether they are different data which the CSA was not obliged to offer

<sup>3)</sup> For an initial discussion of the case, see Laurie G and Gertz R., *ibid.*

Mr Collie. While the CSA submitted that the Barnardisation involved the creation of something new, the SIC claimed that Barnardisation simply allowed the original data to be presented in a different form to protect confidentiality and that the mechanism was intended not to change but rather to alter the focus of the data. The Court began by concurring that the raw data would allow identification in which ward a child was diagnosed as having leukaemia in any year. Following from that, the Court elaborated that there are several ways in which these data can be treated to conceal the actual numbers, one such way being a table containing Y (for yes) and N (for no) in the appropriate cells, showing whether there had been any diagnoses in this year and ward, thus shifting focus from *incidents* to *incidences* of leukaemia. This method was not seen to create information differing from the raw data. The same was deemed true for Barnardisation with the Court focusing on the fact that while at first sight, a material change seems to take place, “the intelligent reader will also be informed by a relative footnote that the numbers which he or she sees have been Barnardised and so cannot be regarded as true numbers”.<sup>4</sup> The Court considered Barnardisation to leave the recipient of the table in the same position as in the case of the Y and N table, thus not providing different information. This, so the Court asserts, results in Barnardised data being different from the raw data only in presentation, not in kind and thus being data held by the CSA.

Second, the question whether the Barnardised data fell under the personal data exemption in section 38 of the FOISA in connection with the DPA was examined.<sup>5</sup> The CSA submitted that this was the case, while the SIC, referring to the *Durant* case,<sup>6</sup> where a narrow interpretation of personal data was chosen — data ‘which relate to’ an individual needed to have that data subject as their focus and had to be of biographical significance, denied this suggestion. Rather, according to the SIC, neither did the Barnardised data have individuals as their main focus, nor were they of biographical significance to the children in question. Biographical significance in this connection means that mere incidental references are not sufficient. As in the first issue, the Court agreed with the submissions of the SIC, stating that the focus had moved away from individual children to the more general incidence of disease in particular wards in particular years.

<sup>4</sup> First Division, Inner House, Court of Session [2006] CSIH 58 XA89/05, Opinion of the Lord President in Appeal by the Common Services Agency against the Scottish Information Commissioner, p. 8

<sup>5</sup> S 1 (1) of the DPA: “personal data” means data which relate to a living individual who can be identified—

(a) from those data, or

(b) from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller,

and includes any expression of opinion about the individual and any indication of the intentions of the data controller or any other person in respect of the individual

<sup>6</sup> *Durant v Financial Services Authority* [2003] EWCA Civ 1746; [2004] FSR 28

<sup>7</sup> Data Protection Act 1998, s. 1 (1)

A third issue, namely the question of the extent of the SIC's powers to require the CSA to provide the Barnardised data, was not discussed as, according to the Lord President, it had been established that the data was held by the CSA.

### III. The Implications of the Decision

Since the appeal was refused, both the decision made by the SIC and the principles established by the Court's reasoning will need to be examined for their potentially far-reaching implications for the CSA and the NHS more generally.

#### 1. *Different or Not Different — That is the Question*

One important question for future requests and also for potential research is how useful Barnardisation actually is as a means to remove oneself from the scope of the DPA. If, as the Court elaborates, Barnardised data no longer constitute personal data, then any data thus processed would no longer fall within the auspices of the DPA. This, however, leads to an important problem raised by the Court's opinion, namely an apparent inconsistency occurring between the two main issues.

Thus, on one hand, the Court stipulates that Barnardised data are no different from the original raw data, only presented differently. However, the Court then proceeds to explain that while the original raw data must be considered personal data, thus falling under the s 38 exemption, the Barnardised data are not, as their focus has shifted. This, however, seems to constitute an inconsistency in the Court's reasoning: If Barnardised data are no different from the raw data, then how can the raw data be classified as personal data, while the Barnardised data do not fall into that category? The only possible way for this to be consistent is if we assume that the shift in focus away from individuals is caused by the different presentation. This, however, seems highly unlikely, in particular when one considers the far-reaching consequences this shift in focus has for the personal data question and the statement by the Court that the different presentation does not result in different data.

This seemingly unsolvable problem suggests that Barnardisation cannot be considered a useful tool to remove oneself from the scope of the DPA. In fact, Barnardisation is only one of a range of Statistical Disclosure Control (SDC) measures available to data controllers. Moreover, it is not suitable for very sparse data tables, a fact which is consistent with guidance that emerged from the Office of National Statistics in October 2006. Additionally, one needs to consider the Court's statement that "the intelligent reader will also be informed by a relative footnote that the numbers which he or she sees have been Barnardised and so cannot be regarded as true numbers".<sup>8</sup> The intelligent reader, in fact, knowing

<sup>8</sup>) First Division, Inner House, Court of Session [2006] CSIH 58 XA89/05, Opinion of the Lord President in Appeal by the Common Services Agency against the Scottish Information Commissioner, p. 8

that the numbers are small and having read the SIC's decision, which spells out in detail the Barnardisation method that the CSA have to use in this case, may well be quite able to derive what the actual raw data was.

## 2. *A Costly Analysis*

A second and more practice-oriented problem that can be deduced from the Court's opinion is raised by the 'data held' argument, which in effect states that if a public authority holds raw data, it automatically holds these data in any imaginable analysed form, as long as the costs for the analysis do not exceed £ 600. Looking at the worst-case scenario, this results in the situation where a public authority may receive numerous requests for the same data in a variety of analysed forms. First, the authority may not have intended for those data to be analysed in that particular way (e.g. producing tables of disclosive data that threaten the privacy of individuals) and, second, while each individual request may fall well beyond the £ 600 benchmark, the summarised costs for the analyses of the data may exceed the budget.

## 3. *Disclosive but Not Personal?*

A third problem is the question of whether data can be disclosive without falling into the category 'personal data' and, if yes, how these data are to be treated and whether this constitutes a gap in the legislation, i.e. 'personal data' are covered, but not 'disclosive data'. Disclosive data in this connection would mean data that, while not falling under the definition provided by s 1 (1) of the DPA, still allow conclusions to be drawn to the identity of the data subjects. The SIC referred to the Washington State Department of Health guidelines on working with small numbers. There, it says that "a count of no events in the cell is clearly no threat to confidentiality".<sup>9</sup> Furthermore, the SIC states in his decision "...some or many of those cells will contain zero. This does not contain personal information and so that information should have been provided..." It is obvious, however, that a request for a listing of all postcodes in Scotland where there have been *no* incidences of a condition is effectively a request for a listing of the postcodes in which cases *have* been found. As some postcodes have only one or very few residents, the implications for privacy are obvious. In other words, zero cells are clearly disclosive of, at the very least, incidences of the disease.

The question this raises is whether these zero cells will have to be classified as personal data in this situation or whether disclosive data of this nature truly constitute a gap in the legislation.

Hence, it will first need to be determined whether a hypothetical request for all postcodes with no occurrence of the disease might fall under s 1 (1) of the DPA.

<sup>9</sup> <<http://www.doh.wa.gov/Data/Guidelines/SmallNumbers.htm>>

Individuals will obviously not be identifiable from the table containing zero cells alone, hence this table cannot be classified as personal data under s 1 (1) (a). It is worth examining, however, whether from the zero cells, together with other information to which the data controller may have access, individuals diagnosed with the rare disease may be identifiable according to s 1 (1) (b).

As mentioned above, the leading case in the UK up to now has been the well-known decision the House of Lords reached in *Durant*,<sup>10</sup> which limited the definition of personal data considerably through the introduction of the concepts of 'biographical significance' of the data and that the putative data subject is the 'focus' of the data to the law. Since then, *Durant* has been confirmed in two other cases. Accordingly, the data must have the data subject as its focus and be of biographical detail. Taking the hypothetical case where the applicant requests only zero cells, i.e. postcodes where no disease has occurred, the focus of the request must be considered to rest on those post codes without occurrences of the diagnosed illness. The remaining few post codes had not been subject of the enquiry. Hence the individuals diagnosed with the disease would not be the focus of the data requested. Nor, obviously, would the requested postcodes be of any biographical significance.

However, s 1 (b) of the DPA adds another possibility and focuses on whether the data controller has additional information in his/her possession, which, when linked with the information requested, will lead to the data subjects being identifiable. Then the data will fall under the 'personal data' category. This, however, raises the question who in this case the data subject is. According to the DPA, "'data subject' means an individual who is the subject of personal data". In our hypothetical case, however, the applicant had not requested postcodes where individuals had been diagnosed with the rare disease. Rather, the applicant asked for postcodes where *none* such individuals live. Can we, then, still speak of the diseased individuals as data subjects? The answer can only be negative. Even if we do not apply *Durant* and accept a broad interpretation of 'personal data', the need for a data subject has never been contested. In this hypothetical case, the request was not for information about individuals — identifiable or not — but rather for the opposite. This allows the conclusion to be drawn that the data in question do not fall under 'personal data' but are still *disclosive* if combined with other information.

#### IV. Conclusion

The Court's decision in the Collie case had been anticipated as a landmark decision for Freedom of Information with regard to health data. Legal scholars had

<sup>10</sup> *Durant v Financial Services Authority* [2003] EWCA Civ 1746

expected some clarification on the issues at stake. Rather, while hailed in the press as a victory for openness and accountability over a culture of secrecy, the problems and inconsistencies listed above demonstrate how this decision has sadly failed to meet those expectations. Instead, there are severe implications for the medical profession with regard to patient privacy: It appears that although data controllers in healthcare may be correct in stating that the data they are asked or ordered to release are potentially disclosive (and therefore a threat to patient privacy), nonetheless the information has to be given. If this decision has to be followed, it needs to be clearly signalled to the General Medical Council as they are responsible for ensuring that doctors comply with ethical guidance that obliges them to protect patient information given in confidence; to the UK Information Commissioner as it alters perceptions of what constitutes personal data; and to patients who may have concerns that the ability of NHS data controllers to prevent release of potentially disclosive data has been significantly weakened.



